

**STATE AGENCY HOME FOR AUTISM AND DEVELOPMENTAL DISABILITIES**  
**WORK GROUP MEETING SUMMARY**  
**August 6, 2008 ♦ 1:00 – 4:30 PM**

**WELCOME**

**Heidi Dix, Asst. Deputy Secretary**  
**Office of the Secretary of Health**  
**and Human Resources**

Heidi welcomed the work group members on behalf of Secretary Marilyn Tavenner. She provided an overview of the work done by the Joint Commission on Health Care last year and reviewed the purpose of the work group. She explained that there would be a public comment period at each meeting and a website would be established to track the progress of the group and provide a forum for stakeholders to submit public comment via the web. Heidi introduced the work group facilitator, Jean Tuller.

Work group members introduced themselves and made a statement regarding their expectations for the outcome of the meeting:

Lee – Come to agreement on issues needing to be addressed

Dana for Fred – People respect one another's views

Martha – Something actually gets done and isn't just more chatter

Katherine – Agree to being one and accepting each other

Jamie – Increased access and support for people with DD

David – Move forward in a way that everyone feels listened to.

Helen – Keep eye on people who receive services and their families

Julie – Listen carefully and learn a lot

Sandy – Come to agreement and advocate for all people with disabilities and not just one population

Kim – Remember to keep needs of people with autism/dd as priority

John – No shots are fired; point to real outcomes on road to getting a DD system

Marie – Consensus about prioritizing challenges and brainstorm real strategies

Bradford – All people with disabilities – no needs greater than others; no hierarchy of disability importance

Tim – Live where you want to live, work a decent job (Linda summary for Tim– Points of view of self advocates taken into consideration)

Linda – establish time line to communicate to constituency groups

Joshua – Keep the waiver flexible

Mary – Major points of developing the plan

Jennifer – Not let points of disagreement hinder getting to the major decisions

Heidi – That we all feel we've moved forward in some way

Jill – Regardless of self-advocates' abilities, adults can get right services and supports

Christina – People to have the right supports and services they need

Linda – Focus on helping people get what they really need with quality comprehensive services

**WORK GROUP PROCESS, MEETING  
OBJECTIVES & PRELIMINARY SCHEDULE**

**Jean Tuller, Facilitator**

Jean facilitated the establishment of ground rules for the work group. The GROUND RULES are:

- One person talking at a time
- No side bars
- Don't rehash anything that has already been decided
- Listen to what everyone has to say – respectfully
- Give time to people to finish their comments
- Develop sub agenda items to focus on one thing at a time
- Decisions will be made by consensus
- Don't get jammed at the end
- Establish a parking lot for some discussion items
- Establish a structure for the public comment period

**STATEMENT OF DMHMRSAS READINESS**

**Frank Tetrick, Asst. Commissioner  
Community Services, DMHMRSAS**

Frank expressed appreciation to the work group for those who participated in the work that was done last year and to OSHHR for taking on the responsibility to make this transition work. Frank shared that he believes that decision made last year, supported by the Secretary, to house services at DMHMRSAS is tied to the work done over the last several years that enforces and honors the principles of person-centeredness. The DMHMRSAS will do everything possible to approach its new responsibilities with this same dedication to person centered principles. Frank indicated that the DMHMRSAS is Aware that there are challenges to moving forward and no one wants to lose their own identity and be subsumed into such a large organization as DMHMRSAS. He shared that the timing is ideal because of the work being done to give greater voice to people at the state government level that have not traditionally had a voice. The DMHMRSAS will do its very best and work together with everyone to achieve best possible outcomes for individuals with developmental disabilities and autism spectrum disorders.

**PUBLIC COMMENT PERIOD**

**Jean Tuller, Facilitator**

One person requested to provide public comment to the work group. Ms. Diane Jeffers, the parent of two children with disabilities, from Northern Virginia offered the following public comment: I have one son who was on the MR Waiver waiting list for 20 years and received a slot only due to my husband being diagnosed with brain cancer. My other son received one of first DD Waiver slots when the program was started. My concern is that my interactions with CSB in Northern VA have not been positive and I

question their ability to serve new disability group(s). They have no knowledge of option of EDCD Waiver. We did not receive a lot of supports for our son over the 20 years he was on the waiting list. I do not want the same thing to happen for the DD Waiver.

**IDENTIFICATION OF TRANSITION CHALLENGES  
PRIORITIZATION OF CHALLENGES TO ADDRESS  
IDENTIFICATION OF INITIAL STRATEGIES & RESOURCES**

**Jean Tuller, Facilitator &  
Work Group**

Members of the work group requested clarification of the committee's scope of responsibility and authority. Heidi clarified that this is an advisory group to the OSHHR and its decisions are not binding. However, the Secretary will consider the advice of the work group in formulating her decisions about the transition plan to DMHMRSAS. Heidi also shared information on her discussion with JLARC regarding its current study on Autism. This study will not be completed in fall of 2009 and is focused on looking at best practices in services compared to what other states do. JLARC and OSHHR will have open communication on the work of the study and this work group. JLARC is in the very early stages of information gathering, but both organizations are willing to make sure work does not go down two different paths. OSHHR is very focused on outcomes, working together in the spirit of continuous learning, and readiness to move forward. Everything is a building block in the legislature and this is a first step to transition service oversight and advocacy to a single state agency. Heidi will post the specific parameters of the JLARC study on the website.

Heidi reiterated that the goal is to move toward a DD system, recognizing that it will not happen overnight.

Identification of transition challenges

Jean facilitated a brainstorming session with the work group on identifying the challenges to transition:

- Identify what our systems are like right now
- What are the problems? What causes the problems?
- What resource issues contribute to problem?
- Having people with DD fit into the service structure
  - Finding providers
  - Becoming a mandated population
- What services are needed as opposed to the waiver that you have now
- What will be the interface with the EDCD Waiver and the new service structure?
- How will your Medicaid program support the new structure?
- What would a new infrastructure for DD look like?
- Funding beyond just the waivers
- Define what developmental disability means in VA
- How would DMHMRSAS be organized to support DD?

- State historically funds groups not individuals in community based services no based in person centered approaches
- Medicaid is funding program, not the services – what service options are needed?
- How does MH & SA fit into the new department?
- Identity of serving individuals as opposed to identify of funding streams and places
- Are we a label-based system or should we consider organizing by service/support/function needs?
- Challenge the assumption of silos
- Accountability measures to serve the larger DD community
- More simple waivers and access
- A lot of different state agencies touch people with DD – don't want to lose services or have insufficient coordination between agencies, regulations
- Culture change within DMHMRSAS will be needed to encompass a wider variety of groups
  - Blueprint
  - Time table
- Adequate training for the workforce – developing the workforce generally
- VA has waiting list which should be addressed but accepted – this needs to change
- What individuals need – focus on services and supports
- Competition for limited resources
- More choice
- Living wage, health care for staff
- Worker registries
- Keeping worker requirements customized to the individual
- Consumer driven services

Following the brainstorming session, themes to the challenges emerged and were agreed to by the work group members.

#### Themes of challenges:

- Infrastructure of DD Agency
  - Cultural issues of people not slots/places
  - People/families equal partners – nothing about us without us
  - Treatment of people with disabilities in our state
- Medicaid support
  - Self directed
  - Wide array of flexible services
- Need for policies and regulations/procedures
  - Interagency collaboration/coordination
- Service issues
  - Access to services
  - Trained funded workforce
  - Self directed
  - Individualized
  - Service Philosophy

The committee then broke into smaller work groups to continue identifying action items for one year and two years related to the four themes of challenges.

1. Infrastructure (small group facilitator: Lee Price)
  - ✓ Offices – functional “DD”
  - ✓ Regulatory change
  - ✓ Groups have to come together
  - ✓ Point of entry issues
  - ✓ Marketing/training
  - ✓ Role of CSBs
  - ✓ Expertise/staffing
  - ✓ Needs and numbers
2. Medicaid Support (small group facilitator: Helen Leonard)
  - ✓ What does it need to look like in 2 years to provide full support to people with DD/MR and DD Waivers
    - a. Single point of entry
    - b. Easy to find
    - c. Seamless system
    - d. Political climate
    - e. DD Umbrella (MR, Autism, CP, Inclusive)
  - ✓ Activities for two years
    - a. Educate line worker
    - b. Family/Individual guide to assist
    - c. 7 Waivers/Different Access
    - d. Medicaid Mentor to 100 (Additional)
    - e. Access to providers
    - f. DD Case management
    - g. MR – CSB case management
    - h. Waivers – continue current admin structure for two years
      - Clarify definitions of services
      - Get funding
      - Identify needed services
      - EDCD as back-up
      - Examine seamless
      - Aggregate cost – service all level of need
      - Address waiting lists
      - Recruit Providers
  - ✓ Long Term Support Waiver
3. Policy/Procedure/Regulations (small group facilitator: Marie Ireland)
  - ✓ Steps over the next year
    - Utilize system transformation grant to provide info and training and assist group

- Utilize cross gov. team work in areas of transition and community focus, etc. (Olmstead)
  - Develop standards for services and case management utilizing JLARC study info
  - Determine roles of VOPA, Partnership and VBPD in setting best practices in VA (ages and spectrum)
  - Crosswalk state regs, policy and philosophy to identify gaps between/among agencies (all ages) – already in process for DMAS, DSS, VDH, DMHMRSAS
  - Develop “roadmap” for individuals to access services from point of entry (to aid in building systems and regs)
  - Improve/create data system for planning purposes (more than we have now)
- ✓ In two years
- System that maximizes potential using person centered practices with community based inclusive focus for all ages
  - The agency will serve as the lead for service delivery and set standards for service delivery and case management including life span planning involving all agencies (one plan)
  - Equitable system for all – availability of services/supports seed programs in areas lacking systems

#### 4. Services (small group facilitators: Jill Egle and Jamie Trosclair)

- ✓ What it would look like
- Everybody who is included needs services to be fit into right place
  - Treat everyone equally
  - Choice of services
  - Age appropriate
  - Limited regulations
  - Housing
  - Transportation
  - Quality Providers
  - Education
  - Job coach drops support
  - Rehabilitation technician
  - Competitive Wages
  - Not barriers – more opportunities
  - Training driven research – best practices
  - Choice of value
  - Personal diagnosis
  - Community – no institutions
  - People with DD driving their own decisions

- Service gaps
  - Money
  - Advertising services
  - Available service gap
  - Case management
  - Providers
  - More training
  - Consumer directed
  - Registry
  - Services are driven by quality
  - No labels
  - Portability of services
  - Personal relationships
  - Privacy protected
  - Being able to be hired
  - Early intervention
  - Waiver wait list and strict criteria
- ✓ Next steps
- The department explore privatization
  - Change its mission
  - Start registry
  - Training program
  - Job training programs
  - Start doing away with institutions
  - Auditing service providers
  - Enhancing licensure
  - Streamline access
  - More advertising
  - Money for services and training
  - Streamline reciprocity
  - Infusion of money

Each work group summarized its action items for the full committee. The full work group will reconvene at 9:00 AM for an all day work session on Wednesday, August 27, 2008 at the Tuckahoe Public Library. Heidi will send out the work session summary by August 20 and will include directions to the next meeting location.